Dear Representative \_\_\_\_\_\_:

I am reaching out on behalf of the International Rett Syndrome Foundation (Rettsyndrome.org). Rett syndrome (RTT) is the most severe neurologic disorder to affect females in childhood, occurring in approximately 1 in 10,000 female births, and more rarely in males. RTT is characterized by a loss of acquired fine and gross motor skills and the development of neurological, cognitive and autonomic dysfunction. Most children with RTT experience cardiac, respiratory, digestive and muscular abnormalities, and are often unable to walk or talk. Further, many children with RTT develop scoliosis and seizures and require lifelong care, even as they live well into adulthood.

[ADD INFORMATION ABOUT YOUR FAMILY’S EXPERIENCE WITH RETT.]

With no approved treatments, care providers can only rely on physical and occupational therapy, speech therapy, and seizure medications to manage the symptoms of disorder. As a rare disease, there are still no approved treatments available for those with RTT, and there is no cure.

We respectfully request that you sign on to the House support letter (http://bit.ly/IRSF-HouseLetter), urging the Chairwoman McCollum (D-MN-4) and Ranking Member Calvert (D-CA-42) of the House Defense Appropriations Subcommittee to include Rett syndrome as a research topic eligible for funding through the Peer Reviewed Medical Research Program (PRMRP) in the Fiscal Year 2022 Defense Appropriations bill. This listing will allow researchers to access funds to develop new treatments toward a cure for RTT.

Sincerely,

(Name and home address)